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DOI:

[10.1016/j.jalz.2017.06.2267](https://doi.org/10.1016/j.jalz.2017.06.2267)

Document Version

Version created as part of publication process; publisher's layout; not normally made publicly available

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Citation for published version (APA):

Sleeman, K., Perera, G., Stewart, R., & Higginson, I. J. (2017). Predictors of emergency department attendance by people with dementia in their last year of life: Retrospective cohort study using linked clinical and administrative data. *Alzheimers & Dementia*, 14(1), 20-27. <https://doi.org/10.1016/j.jalz.2017.06.2267>

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Featured Article

Predictors of emergency department attendance by people with dementia in their last year of life: Retrospective cohort study using linked clinical and administrative data

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Abstract

Introduction: A fall in hospital deaths in dementia has been interpreted as indicating an improvement in end-of-life care. Whether other indicators of quality of end-of-life care, such as emergency department (ED) attendance, show a similar trend is unclear.

Methods: Retrospective cohort study using electronic medical records from a large mental health care provider, linked to national mortality and hospital use data (2008–2013).

Results: Of 4867 patients, 78.6% (3824) had at least one ED attendance during their last year of life (mean 2.13, standard deviation 2.34, range 0–54). ED attendance increased over the time period (incidence rate ratio 1.62, 95% confidence interval 1.46–1.80 for 2012–2013 compared with 2008–2009).

Discussion: ED attendance in the last year of life for people with dementia is common and is increasing. Policy makers must pay attention to a broader range of indicators of poor end-of-life care alongside the place of death.

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Keywords:

Dementia; End-of-life; Emergency department; Palliative; Policy

1. Introduction

Over the past decade there has been a strong policy focus in the UK and elsewhere on dying out of hospital as a marker of good quality end-of-life care [1,2]. A fall in hospital deaths and a reciprocal increase in home deaths during this time period have been considered to suggest success of these strategies [3]. However, the place of death only provides a snapshot of the care received by a patient at the

end of their life, and does not tell us about the care received during their last weeks and months.

Emergency department (ED) visits for people who are approaching the end-of-life can be distressing for patients and families and challenging for staff, and are considered potentially preventable in a high proportion of cases [4]. At a population level, ED use toward the end-of-life has been used to indicate poor quality of care [5]. For people with dementia, ED visits and acute hospital care can lead to cognitive and physical deterioration with increased risk of hospital acquired infections, bedsores, and worsening of behavioral problems [6]. However, ED attendance among people with dementia remains common [7], and studies in the United States have shown that ED use rises sharply as death approaches [8]. Whole population mortality data analysis has shown that hospital deaths in dementia in England began falling in 2005/2006 [9]. Whether other indicators of poor

Conflicts of interest: The authors have declared that no conflict of interest exists.

Data sharing: The data set analyzed during the present study is not publicly available, please contact the NIHR Maudsley Biomedical Research Centre (BRC) Clinical Record Interactive Search (CRIS) for more information.

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<http://dx.doi.org/10.1016/j.jalz.2017.06.2267>

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quality end-of-life care in dementia such as ED attendance show a similar trend is not known.

Routinely collected data, for example, mortality data, are increasingly used in end-of-life care research and offers the methodological advantage of negating the challenges of primary data collection in this potentially vulnerable population [10]. Furthermore, routine data analysis is usually more economical and timely than primary data collection, and can be carried out for large population-based samples [5]. However, research in this area is limited by a paucity of relevant clinical information in administrative data and incomplete recording of data [11]. Linking administrative with clinical data can overcome these limitations, while allowing examination of outcomes in naturalistic samples and settings [12]. The aim of this study was to use linked data from a large mental health database to examine the frequency, and identify predictors, of ED attendance among people with dementia in their last year of life.

2. Methods

2.1. Setting and data source

This retrospective observational study used data from the South London and Maudsley National Health Service (NHS) Foundation Trust (SLAM) Biomedical Research Centre Case Register and the Clinical Record Interactive Search (CRIS) data extraction tool. This data resource has been described previously [13–17]. It provides researcher access to full anonymized copies of electronic medical records from SLAM, one of Europe's largest mental health care providers covering a geographic catchment of 1.2 million residents in four boroughs of South London. SLAM delivers a comprehensive range of services, including dementia assessment and treatment. Data are currently archived on more than 300,000 cases with a range of mental disorders.

2.2. Population

The records of all patients with a diagnosis of dementia recorded in SLAM and who were aged 60 years or older at death were retrieved from the SLAM Biomedical Research Centre Case Register. Diagnosis of dementia was determined from structured fields in the source record (based on ICD-10 codes F00x-03x) and supplemented by a bespoke natural language processing algorithm using General Architecture for Text Engineering software [18]. This extracts information from unstructured text data within clinical records (including correspondence and case notes), returning text strings associated with diagnostic statements [13,19,20]. CRIS data have been linked with Office for National Statistics (ONS) death certification data, and this linkage was used to identify cohort members who had died, restricting the analysis to this group. CRIS is also linked to Hospital Episodes Statistics (HES), a record-based system covering all NHS Trusts in England, which was used to determine ED attendance during the last 12 months of life.

Because the HES-ED linkage is only available in CRIS from April 1, 2007, the cohort was restricted to those who died after April 1, 2008 so that 12 months of HES-ED data were available for all patients before death.

2.3. Covariates

CRIS was used to extract data on age, gender, ethnicity (White British, Other White, African Caribbean, other, not known) and recorded dementia subtype (Alzheimer's disease, vascular, unspecified, Lewy body, unknown). Socio-economic status was estimated from the 2015 Index of Multiple Deprivation, a measure of relative deprivation for small areas termed Lower Super Output Areas (LSOAs) in England, with LSOAs ranked from 1 (most deprived) to 32,844 (least deprived). Index of Multiple Deprivation was derived from the LSOA associated with the patient's most recent address (at the time of death) and converted into quintiles for ease of interpretation. Dementia severity was estimated from the most recently recorded Mini-Mental State Examination (MMSE) score, drawn from a structured field in the source record and a further General Architecture for Text Engineering information extraction application [13,17]. The most recent Health of the Nation Outcome Scale (HoNOS) was also ascertained from the source record. HoNOS is a functional outcome measure used routinely in mental health care and comprising 12 subscales each rated 0 (no problem) to 4 (severe or very severe problem). We dichotomized the HoNOS scores (scores of 0 and 1 were grouped as no or minor problems, scores of 2, 3, and 4 represented mild to severe problems) to facilitate interpretation. Care home residence was determined from a data linkage to residential postcode. Linkage with ONS death certification data provided information on the place of death, which was categorized as private residence/own home, hospice, hospital, care home (including residential and nursing homes) and "other" (e.g., prisons, street). Place of death was categorized from free text provided by ONS by one author (K.E.S.) and independently checked by a second author (G.P.). Where there were discrepancies these were discussed and a category was agreed. The time interval (in months) between the last face-to-face contact by a SLAM staff member and death was determined using the date of death from ONS mortality data. The age at death was determined from the date of death in ONS mortality data and the date of birth in CRIS. Information on ED attendance, mode of arrival (ambulance or other), referral mode (via GP, emergency services, or self-referred), outcome of ED attendance (admission to hospital, discharge with GP follow-up, or discharge with no follow-up), and time of attendance was determined using the HES-ED linked data. Out of hours was defined as 8 PM to 8 AM on weekdays, or any time on Saturday, Sunday, and Bank Holidays.

The primary outcome was number of ED attendances in the last year of life, modeled as a continuous variable.

2.4. Statistical analysis

At the level of the ED attendance, descriptive statistics were used to describe mode and time of attendances and outcome following ED attendance. Chi-square tests were used to examine differences in the mode, time of attendance, and outcome according to proximity to death. At the patient level, descriptive statistics were used to describe the study population in terms of demographic and clinical variables. Negative binomial regression analysis was used to investigate the factors associated with ED attendances in the last year of life, using an adapted theoretical model [21]. Negative binomial regression was chosen in preference to Poisson regression as the data were overdispersed. For the multivariable model, explanatory variables were selected according to a priori hypotheses and significance in unadjusted analyses ($P < .1$). In light of missing data for HoNOS and MMSE, a sensitivity analysis was run with these variables removed. Analyses were performed using STATA version 13 (StataCorp, College Station, TX, USA).

2.5. Patient involvement

Patients and caregivers were involved in the planning and interpretation of this study.

2.6. Ethics statement

The source database is approved for secondary analysis by the Oxfordshire Research Ethics Committee C (reference 08/H0606/71+5).

3. Results

Using CRIS, 4869 patients who had a clinical diagnosis of dementia and who had died were identified. One patient with unknown gender was removed. In addition, one outlier patient in whom there were 218 ED attendances in the last year of life was removed, leaving 4867 patients in the final analysis. Most patients were women (61.3%), and the mean age at death was 85.3 years (standard deviation [SD] 7.4) (increase from 85.1 years [SD 7.3] in 2008–2009 to 85.7 years [SD 7.3] in 2012–2013). The most common ethnicity was White British (71.9%). Compared with the National distribution, the cohort was relatively deprived. The most common dementia diagnosis was Alzheimer's disease (40.4%), followed by vascular dementia (25.4%). MMSE score was available for 79.3% patients, and the most recently recorded mean score was 15.8 (SD 6.8). HoNOS data were available for 88% of patients, and the most common problems recorded in HoNOS were cognitive (90.6%), daily living problems (80.3%), and physical problems (72.0%). The mean time interval between last face-to-face contact in SLAM and death was 16.1 months (SD 19.3). Most of the cohort died in hospital (48.1%) or in a care home (42.4%). Death at home (8.4%) or in a hospice (1.0%) was less common. The cohort size increased over the observation

period from 833 deaths in 2008 to 2009 (17.1% cohort) to 1141 deaths in 2012 to 2013 (23.4% cohort) (Table 1).

During their last year of life, the 4867 patients attended the ED 10,361 times. Referral of patients to the ED was via the emergency services in 35.1% of attendances (3637), via self in 17.6% (1820), via the GP in 5.6% (557), and other in 41.8% (4327). A total of 91.1% of attendances were by ambulance and 47.3% of ED attendances occurred out of hours. A total of 72.7% of ED attendances (7528) resulted in hospital admission, 15.8% resulted in discharge, and 4.9% in discharge with GP follow-up. One hundred eighty-three patients died in the ED (1.8% of attendances, 3.8% of cohort). The frequency of ED attendance increased the closer patients were to death, with 24.6% (2546) of all ED attendances occurring in the last month of life (Fig. 1). ED attendance in the last month of life was more likely to be after emergency services referral and less likely to be after GP or self referral ($\chi^2 = 47.10$, $P < .001$) compared with ED attendance in months 2 to 12 before death and more likely to be by ambulance ($\chi^2 = 90.58$, $P < .001$). ED attendance in the last month of life was more likely to be out of hours ($\chi^2 = 11.72$, $P = .001$).

Of the 4867 patients in the cohort, 78.6% (3824) had at least one ED attendance during their last year of life; 44.5% (2164) of the cohort had at least one ED attendance in their last month of life, and 20.9% (1017) had at least one ED attendance in their last week of life. The mean number of ED attendances per patient during the last year of life was 2.1 (SD 2.3, range 0–54) and increased over the time period studied from 1.6 (SD 1.9, range 0–14) during 2008 to 2009 to 2.4 (SD 2.5, range 0–54) during 2012 to 2013.

In unadjusted negative binomial regression models male gender, younger age at death, more recent date of death, a diagnosis of vascular dementia, unspecified, or other dementia (compared with Alzheimer's disease), African Caribbean ethnicity (compared with White British), higher MMSE (less severe cognitive impairment), and higher severity measures on HoNOS physical health, depression, "other mental" problems, and problems with living condition subscales were associated with greater number of ED attendances. Living in a more affluent area, being resident in a care home, and a longer time between the last face-to-face contact and death were associated with a smaller number of ED attendances.

In the multivariable model, the following factors remained significantly associated with increased number of ED attendances during the last year of life: male gender, more recent year of death, HoNOS depression severity, higher cognitive function (MMSE score), and diagnosis of vascular dementia. A longer interval between the last face-to-face contact in SLAM and death, being resident in a care home, and living in the most affluent areas were associated with fewer ED attendances (Table 2; Fig. 2). A sensitivity analysis with HoNOS and MMSE removed gave similar results, with the exception that increasing age became significantly associated with reduced likelihood of ED attendance.

Table 1
Population characteristics

Characteristic	All (n = 4867)	At least one ED attendance in last year of life (%) (n = 3824)
Age (mean, SD)	85.3 (7.4)	85.2 (7.3)
Age band		
60–69	157	118 (75.2)
70–74	284	235 (82.7)
75–79	639	508 (79.5)
80–84	1051	853 (81.2)
85–89	1385	1093 (78.9)
≥90	1351	1017 (75.3)
Gender		
Women	2984	2278 (76.3)
Men	1883	1546 (82.1)
Ethnic group		
White British	3500	2742 (78.3)
Other White	518	399 (77.0)
African Caribbean	427	348 (81.5)
Other	188	164 (87.2)
Not known	234	171 (73.1)
IMD quintile (n = 4831)		
1 (Most deprived)	1430	1144 (80.0)
2	1695	1322 (78.0)
3	878	691 (78.7)
4	476	385 (80.9)
5 (Most affluent)	352	263 (74.7)
Primary diagnosis		
Alzheimer's disease	1965	1533 (78.0)
Vascular dementia	1238	972 (78.5)
Unspecified dementia	1064	843 (79.2)
Other dementia	555	436 (78.6)
Lewy body dementia	45	40 (88.9)
HoNOS score (subscales)*		
Agitation score 0–1	3278	2629 (80.2)
Agitation score ≥2	1015	788 (77.6)
Self injury score 0–1	4245	3386 (79.8)
Self injury score ≥2	48	31 (64.6)
Drinking and drugs score 0–1	4220	3356 (79.5)
Drinking and drugs score ≥2	73	61 (83.6)
Cognitive impairment score 0–1	402	323 (80.3)
Cognitive impairment score ≥2	3887	3092 (79.5)
Physical health score 0–1	1204	936 (77.7)
Physical health score ≥2	3089	2481 (80.3)
Hallucinations/delusions score 0–1	3789	3019 (79.7)
Hallucinations/delusions score ≥2	484	379 (78.3)
Depression score 0–1	3796	3015 (79.4)
Depression score ≥2	484	389 (80.4)
Other mental health score 0–1	3209	2545 (79.3)
Other mental health score ≥2	1053	845 (80.2)
Relationship score 0–1	3449	2753 (79.8)
Relationship score ≥2	816	638 (78.2)
Daily living score 0–1	844	680 (80.6)
Daily living score ≥2	3438	2725 (79.3)
Living conditions score 0–1	3720	2941 (79.1)
Living conditions score ≥2	505	412 (81.6)
Occupational score 0–1	2649	2110 (79.7)
Occupational score ≥2	1516	1203 (79.4)
MMSE (mean, SD) n = 3861	15.9 (6.9)	16.0 (6.8)
Time since last mental health care contact before death (months, mean)	16.1 (range 0–110.8)	14.2 (range 0–107.5)

(Continued)

Table 1
Population characteristics (Continued)

Characteristic	All (n = 4867)	At least one ED attendance in last year of life (%) (n = 3824)
Care home residence		
Yes	1783	1336 (74.9)
No	3084	2488 (80.7)
Year of death		
2008–2009	833	571 (68.5)
2009–2010	876	717 (81.8)
2010–2011	987	799 (81.0)
2011–2012	1030	807 (78.3)
2012–2013	1141	930 (81.5)

Abbreviations: ED, Emergency Department; HoNOS, Health of the Nation Outcome Scale; IMD, Index of Multiple Deprivation; SD, Standard deviation.

*Missing data varied for subcomponents of HoNOS, and was excluded when calculating percentages.

4. Discussion

ED attendance among people with dementia who are approaching the end-of-life is common, with three quarters of patients having at least one ED attendance in their last year of life. These findings are similar to data from the United States and Australia, where 81.1% and 73.0% of people with dementia had an ED attendance in their last year of life, respectively [22].

4.1. Factors associated with ED attendance

We found that the likelihood of ED attendance in the last year of life has increased over time; people who died in 2012 to 2013 were more likely to have an ED attendance in their last year than people who died in 2009 to 2010. This trend is concerning, and reflects a similar trend in the United States where hospitalization of people with dementia increased between 2000 and 2009 [23]. Although it is known that emergency admissions among people aged more than 65 years in England increased between 2001 and 2012 [24], to our knowledge ours is the first evidence of increasing ED attendance for people in their last year of life.

In our study, being resident in a care home was associated with reduced likelihood of ED attendance. This suggests that care home residence might “protect” patients against transitions in care setting close to death, and that increasing care home bed capacity is likely to play an important role in reducing pressure on emergency hospital care. A similar association has been shown for death in hospital [25]. Although care home capacity has increased in some parts of England in recent years, other areas have seen a loss of care homes [26]. Given the projected increase in prevalence of dementia with population aging [27], this issue requires urgent attention.

Being resident in a more deprived area was positively associated with ED attendance. A similar association

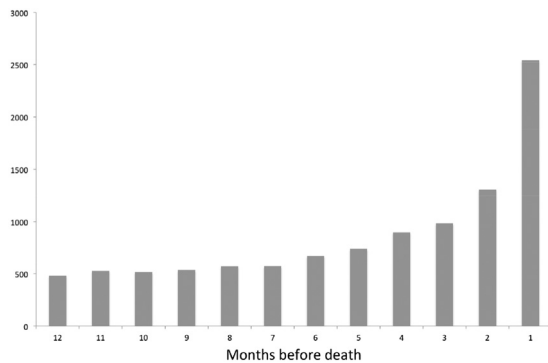


Fig. 1. Frequency of ED attendance by proximity to death in months ($n = 10,361$ attendances); 24.6% ($n = 2546$) of ED attendances in the last year of life occurred in the month before death. Abbreviation: ED, Emergency Department.

has been shown in people with cancer attending the ED in the last month of life [28] and among people with dementia who died in hospital [9]. There is evidence

that people living in less deprived areas may have better access to specialist palliative care (hospice) services [29], which could help mitigate against ED attendance [30].

The association of vascular dementia with ED attendance may reflect the unpredictable nature of deterioration in this condition. In contrast with previous studies that show functional impairment is a driver of health care utilization [31,32], we did not find that patients with severe physical problems were more likely to attend the ED. This may be because the mean interval between last being seen in SLAM and death was 17 months, and so the final recorded HoNOS score may not reflect perfectly the patient's problems close to death. Despite this limitation, our data did show that less severe cognitive impairment was associated with more ED attendances. Other studies have shown similar results [33], although some have found no association between dementia severity and ED transition among nursing home residents [34].

Table 2

Multivariable regression investigating factors associated with ED attendance in the last year of life

Covariates (simultaneously entered)	IRR ($n = 3377$)	Lower CI	Upper CI	P value
Male gender	1.16	1.09	1.24	<.001
Age at death (per year increase)	1.00	0.99	1.00	.208
Ethnic group				
White British	Ref	Ref	Ref	Ref
Other White	0.99	0.89	1.09	.776
African Caribbean	1.07	0.95	1.19	.255
Other	1.08	0.92	1.27	.327
Not known	1.19	0.84	1.69	.326
IMD quintile				
1 (Most deprived)	Ref	Ref	Ref	Ref
2	0.92	0.85	0.99	.036
3	0.85	0.77	0.93	.001
4	0.94	0.83	1.05	.268
5 (Most affluent)	0.79	0.69	0.91	.001
Primary diagnosis				
Alzheimer's disease	Ref	Ref	Ref	Ref
Vascular dementia	1.16	1.07	1.26	<.001
Unspecified dementia	1.07	0.99	1.17	.105
Other dementia	1.04	0.94	1.16	.441
Lewy body dementia	1.03	0.76	1.40	.849
Problem HoNOS scores (subscale scores 2–4)				
Physical health	1.04	0.96	1.12	.346
Depression	1.12	1.01	1.24	.030
Other mental health	1.01	0.94	1.09	.707
Living conditions	1.04	0.95	1.15	.391
MMSE score (per unit increment)	1.01	1.00	1.01	.021
Time since last mental health care contact before death (per month increment)	0.99	0.98	0.99	<.001
Care home residence	0.81	0.75	0.87	<.001
Year of death				
2008–2009	Ref	Ref	Ref	Ref
2009–2010	1.28	1.14	1.44	<.001
2010–2011	1.47	1.31	1.64	<.001
2011–2012	1.40	1.26	1.57	<.001
2012–2013	1.62	1.46	1.80	<.001

Abbreviations: CI, confidence interval; ED, Emergency Department; HoNOS, Health of the Nation Outcome Scale; IMD, Index of Multiple Deprivation; IRR, incidence rate ratio; MMSE, Mini-Mental State Examination; SD, Standard deviation.

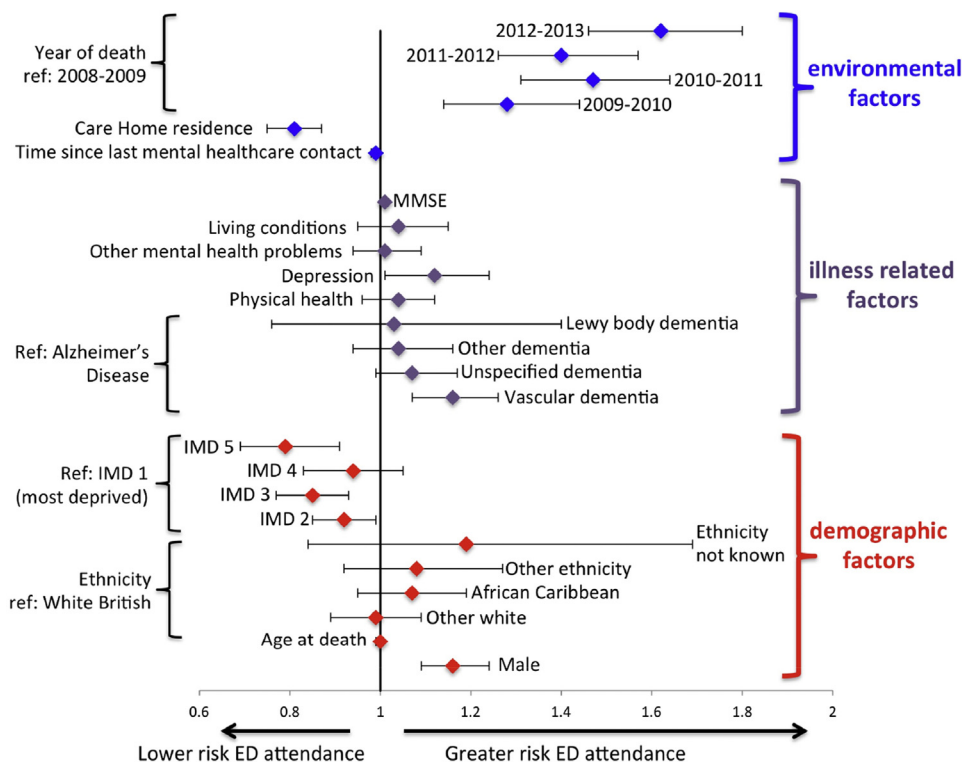


Fig. 2. Environmental, illness-related, and demographic factors associated with ED attendance in last year of life for people with dementia. Red—demographic factors; purple—illness relative factors; blue—environmental factors. Abbreviations: ED, Emergency Department; IMD, Index of Multiple Deprivation.

We found that the frequency of ED attendance among people with dementia increases dramatically as death approaches. A total of 44.5% of our cohort had an ED attendance in their last month of life, and these attendances were more likely to be emergency referrals, to be by ambulance, and to be out of hours, suggesting that these visits are unplanned and precipitated by an acute crisis. Although we cannot determine whether attendances were potentially avoidable, our cohort comprised physically and cognitively frail older people, and the high frequency of ED attendance close to death is concerning.

4.2. Strengths and limitations of the study

This study is the first to examine the factors associated with ED attendance among people with dementia in the last year of life in England, using linked clinical and administrative data. The use of a clinical database enabled us to examine variables, such as the degree of cognitive impairment, and outcome measures that are not available in routine administrative data. Importantly, these variables were available for those who did and those who did not have ED attendances. The use of a clinical database was to identify our cohort negates bias from incomplete death certification of dementia [11].

The limitations of this study are that the data are restricted to those patients seen in a specialist setting, which may limit the generalizability, and future studies should attempt to

replicate the findings in different populations. Predictive factors are limited to those available in routinely collected clinical and administrative data. For example, information about social support was limited to the relevant HoNOS subscale, and detailed information on informal caregivers was not known. No information was available regarding patients' preferences or wishes, the presence or absence of advance directives, or the decision-making processes leading to ED attendance, and future research to explore these areas is needed. The interval between the last face-to-face clinical contact and death was lengthy in many cases, meaning some recorded clinical variables (such as those derived from HoNOS) may not perfectly represent the clinical picture nearer to death. Although we were able to include care home residence in our model, we were not able to include the number of care home beds available in the local area. Finally, our data do not allow us to determine whether the ED attendances were potentially avoidable or the quality of care in the different settings.

4.3. ED attendance as a marker of quality of end-of-life care

End-of-life quality indicators derived from routinely collected data are intended to provide a measure of the quality of care across systems, rather than to judge the quality of care for individual patients. Such indicators were first developed for use in cancer [5,35], and have subsequently been

used in other populations including the elderly [36] and people with dementia [37].

Dementia is a terminal illness and, like cancer, it is characterized by an increase in distressing symptoms toward the end-of-life [38]. In one study of people with advanced dementia, 96% of family caregivers reported that comfort was the primary goal of care [38]. Although ED attendance may be necessary to reduce discomfort (e.g., after a fracture), such circumstances have been found to be infrequent [38].

For people with dementia, high rates of ED attendance near the end-of-life may indicate inadequate availability of community care, a paucity of advance directives, or lack of focus on patients' quality of life. However, dying is a profoundly personal experience. Future development of routinely collected data to include person-centered outcome measures validated for use in people approaching the end-of-life (e.g., pain control, quality of communication, and psychological well-being) would greatly enhance the value of such analyses [39].

5. Conclusions

ED attendance among people with dementia in their last year of life is common and is associated with demographic, illness-related and environmental factors. The strong association between ED attendance and environmental factors is of particular importance given the potentially modifiable nature of these. Care home residence was found to mitigate against ED attendance. In light of the dual pressures of a projected increase in prevalence of dementia and a loss of care home beds in some parts of England [26], investing in care home (or similar) capacity is urgently needed to avoid unnecessary pressure on emergency care. Although the proportion of people with dementia dying in hospitals has fallen [9], our data show that ED attendance in the last year of life follows the opposite trend. We recommend that policy makers consider a broader range of indicators of the quality of end-of-life care alongside the place of death.

Acknowledgments

Funding: K.E.S. is funded by a National Institute for Health Research (NIHR) Clinician Scientist Fellowship (CS-2015-15-005) and has received funding from Cicely Saunders International and the Academy of Medical Sciences (Starter Grant for Clinical Lecturers [AMS-SGCL10-Sleeman], supported by The Wellcome Trust, Medical Research Council, British Heart Foundation, Arthritis Research UK, the Royal College of Physicians and Diabetes UK). The data resource and G.P. and R.S. are funded by the NIHR Biomedical Research Centre and Dementia Biomedical Research Unit at South London and Maudsley NHS Foundation Trust and King's College London. I.J.H. is an NIHR Senior Investigator. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR, or the Department of Health.

Authors' contributions: K.E.S. conceived the idea for this study and performed the analysis with help from GP. K.E.S., R.S., and I.J.H. contributed to interpretation. K.E.S. wrote the article with input from all authors. All authors read and approved the final manuscript.

We thank Mr Hitesh Shetty, Institute of Psychiatry, Psychology and Neuroscience, King's College London for support in preparing the data extraction.

Transparency declaration: K.E.S. affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; no important aspects of the study have been omitted; and any discrepancies from the study as planned have been explained.

RESEARCH IN CONTEXT

1. Systematic review: Using PubMed, we identified and reviewed publications reporting on the frequency of, and factors associated with, Emergency Department (ED) attendance among people with dementia who were approaching death.
2. Interpretation: ED attendance among people with dementia in the last year of life is common and has increased over time. Given the projected increase in prevalence of dementia, our data suggest that investment in care home capacity is urgently needed to mitigate against rising ED attendance near to the end-of-life.
3. Future directions: Future studies should investigate trends in other indicators of potentially aggressive care for people with dementia approaching the end-of-life, such as hospital transitions and intensive care unit admissions. For a decade, national policies have relied on the place of death as an indicator of the quality of end-of-life care. Policy makers must now consider a broader range of indicators of the quality of end-of-life care, taking into account not just where a person dies but the care they receive during the preceding months.

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